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Citation for published version:

Ho, I, Holloway, A & Stenhouse, R 2020, 'Understanding HIV-positive drug users' experiences of taking highly active antiretroviral treatment: The identity-value-conscious engagement model', *Journal of Clinical Nursing*. <https://doi.org/10.1111/jocn.15228>

Digital Object Identifier (DOI):

[10.1111/jocn.15228](https://doi.org/10.1111/jocn.15228)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Journal of Clinical Nursing

Publisher Rights Statement:

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Understanding HIV-positive drug users' experiences of taking Highly Active Antiretroviral Treatment: the Identity-Value-Conscious engagement Model

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Running head: Drug users' treatment experiences

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/JOCN.15228](https://doi.org/10.1111/JOCN.15228)

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Acknowledgement: Firstly, SSH would like to express her gratitude to the College of Arts, Humanities and Social Sciences Research Awards for financially supporting her PhD studies. Moreover, we also thank our colleagues from Nursing Studies, University of Edinburgh for their insight and expertise that greatly assisted this research. In terms of study recruitment, we would like to deeply express our gratitude to the HIV nurse specialist Chung-Ching Shih, Dr Wang Huei Sheng, Mr. Chih Wei Lee, and Dr. Sen Chieh (Paul) Hsu for their support. Last but not least, we would like to give our heartfelt thanks to the participants for their support of this study.

Conflict of interest: None

Funding: The cost of travelling and accommodation for fieldwork was funded by the Innovative Initiative Grants (Project ID GR002105), University of Edinburgh.

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Article type : Original Article

Understanding HIV-positive drug users' experiences of taking Highly Active Antiretroviral Treatment: the Identity-Value-Conscious engagement Model

Abstract

Aim: To explore HIV-positive drug users' experiences of taking antiretroviral medications in Taiwan, and further develop a conceptual model that can be used to understand their adherence to the long-term treatment.

Background: The global vision of ending AIDS by 2030 cannot be achieved without addressing HIV-positive drug users' experience of taking antiretroviral treatment. There remains a paucity of qualitative evidence on HIV-positive drug users' experiences of taking antiretroviral medications globally and in East Asia. Nurses play a key role in supporting HIV-positive drug users throughout their treatment process. Therefore, it is pivotal to understand HIV-positive drug users' experiences of managing long-term anti-HIV treatment.

Design: This qualitative study drew on a constructivist grounded theory approach to achieve the aims. Semi-structured in-depth interviews with 22 HIV-positive drug users were

conducted in Taiwan between September 2015 and July 2016. Data were analysed using Charmaz's coding principles. The integration and formation of the model began with focused coding and proceeded through the subsequent analytic process. The reporting of this study was based on the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

Results: This study shows that integrating HIV-positive identity into sense of self laid a solid foundation for the acceptance of self and antiretroviral treatment. Valuing of antiretroviral treatment played a central role in driving their medication-taking behaviour. While valuing the treatment appeared to drive participants' behavioural change, data revealed that conscious engagement was an important element for their behaviour maintenance.

Conclusion: The evidence from this study can extend our knowledge of the mechanisms that influence the change and maintenance of HIV-positive drug users' adherence to antiretroviral treatment.

Relevance to clinical practice: The Identity-Value-Conscious engagement Model developed and proposed in this study can serve as a guide for the development of tailored adherence assessment and associated nursing interventions for this population.

KEYWORDS: adherence; antiretroviral treatment; drug users; grounded theory; HIV; qualitative research

Introduction

The Joint United Nations Programme on HIV/AIDS (UNAIDS) in 2014 set out a goal to end Acquired Immunodeficiency Syndrome (AIDS) by 2030. To reach this global visionary goal, it is widely recognised that more than 95% of prescribed Highly Active Antiretroviral Therapy (HAART) medications should be taken for complete viral suppression (World Health Organisation (WHO), 2013). However, a growing body of evidence indicates that HIV-positive drug users are less likely to access HIV care and adhere to treatment regimens compared to other HIV subgroups (Ware, Wyatt, & Tugenberg, 2005; Wasti, Simkhada, Randall, Freeman, & van Teijlingen, 2012). Suboptimal adherence can lead to opportunistic infections, drug resistance, and limited treatment options (Lima et al., 2008; Meresse et al., 2014). In HIV-positive drug users, Tuberculosis is particularly common as a result of poor adherence (WHO, 2017). It is therefore important to understand the mechanisms that support HAART adherence in HIV-positive drug-using populations in order to promote adherence, optimise health and reduce transmission.

Research to date has tended to focus on measuring the rates of drug users' adherence to HAART rather than gaining insight into the mechanisms underlying their HAART-taking behaviour (Mann et al., 2012; Authors, 2019; Waldrop-Valverde, Dong, & Ownby, 2013). There remains a paucity of qualitative evidence on HIV-positive drug users' experiences of taking HAART globally. Only 11 qualitative studies from USA, Canada, Russia, Ukraine, Spain and India were identified prior to this study (Chakrapani et al., 2014; Batchelder et al., 2013; de la Hera, Davo, Ballester-Añón, & Vioque, 2011; McNeil et al., 2017; Mimiaga et al., 2010; Pach, Cerbone, & Gerstein, 2003; Rhodes & Sarang, 2012; Small, Wood, Betteridge, Montaner, & Kerr, 2009; Ware et al., 2005; Witteveen & Ameijden, 2002).

A multitude of factors have been identified in the aforesaid 11 studies to influence their adherence to HAART, including stigmatisation, active drug use, motivation, side effects of HAART, accessibility, health care professionals' attitude towards drug users, and forgetfulness (Chakrapani et al., 2014; Batchelder et al., 2013; de la Hera, Davo, Ballester-Añón, & Vioque, 2011; McNeil et al., 2017; Mimiaga et al., 2010; Pach, Cerbone, & Gerstein, 2003; Rhodes & Sarang, 2012; Small, Wood, Betteridge, Montaner, & Kerr, 2009; Ware et al., 2005; Witteveen & Ameijden, 2002). Whilst these studies provide insight into the factors that can influence HIV-positive drug users' adherence to HAART, the findings tend to be descriptive in nature and little is known about the mechanisms that influence their adherence through a theoretical lens. Uncertainty still exists about the interrelationships between the factors that impact adherence, and how the factors collectively or interactively influence drug users' HAART-taking behaviour. This formed the basis of the research inquiry for this study in respect to developing a theoretical understanding of HIV-positive drug users' HAART-taking behaviour.

Health behaviour theories/models

To date, several theories have been developed and applied to explain personal and social determinants of behaviour and to guide and refine health-related interventions (Munro, Lewin, Swart, & Vomink, 2007), such as the Health Belief Model (Rosenstock, Strecher, & Becker, 1994), Theory of Planned Behaviour (Ajzen 1991), Social Cognitive Theory (Bandura, 1991 and 2001), Information-Motivation-Behavioural skills Model (Fisher & Fisher, 1992), and Motivation Protection Theory (Weinstein, 1993). Of these theories/models, Information-Motivation-Behavioural skills Model is the only model that has been extensively employed in research to explain HIV-positive individuals' adherence to antiretroviral treatment (Fisher, Fisher, Amico, & Harman, 2006; Amiko, Toro-Alfonso, & Fisher, 2005). However, this model does not provide adequate theoretical explanations regarding how motivation is defined and how psychosocial factors can influence behaviour change and maintenance. Across the

health behaviour theories/ models, there is an increased recognition of similar and overlapping constructs. For instance, the Health Belief Model, Information-Motivation-Behavioural Skills Model, Motivation Protection Theory, Theory of Planned Behaviour, Social Cognitive Theory all provide a cost-benefit analysis component in which an individual weighs pros and cons of an action and then leads to motivation for (not) taking the action. Whilst the theories and models provide theoretical implications of what can trigger individual behaviour, one's decision to take an action is not always rational and intentional but could be emotionally triggered, unintentional and context-specific.

HIV and drug use, for instance, have been associated with behaviours or characteristics that are deviant from social norms, such as promiscuity, crime, sex work, and homosexuality (Logie, James, Tharao, & Loutfy, 2011). These historic associations could lead people to generate negative impressions and prejudice towards HIV-infected drug users. When these discrediting attributes are incongruous with the stereotype of what a given type of individual should be, stigma could occur (Goffman, 1963). Affected individuals' experiences of intersectional stigma could exert significant social and psychological effects (Goffman, 1963). For instance, in a cross-sectional study by Nachega et al. (2012), it was reported that depression, isolation, non-disclosure of HIV status and stigma/discrimination were significantly common among people living with HIV. In particular, Asia-Pacific region had the highest rate of perceived stigma (71%) compared to Europe (49%), North America (41%), Africa (41%) and Latin America (29%) (Nachega et al., 2012). In the same vein, Charles Cooley (1983) in his looking-glass theory encapsulated the idea that our sense of self, of who we are, is intimately shaped by those around us, by our emotions and by perceived judgement; therefore, suggesting that it changes depending on which society we grow up in and situate ourselves. When confronting a sudden or stigmatised illness, affected individuals could reflexively interpret the illness that is bestowed upon them by others and themselves, leading to change in their sense of self (Pierce, Kostova, & Dirks, 2003). Illness experience was proposed by Karnilowicz (2011) and Bury (1982) as an epiphany that could alter an individual's fundamental meaning structures and result in reassessing his/her sense of self during the process of the illness. Nonetheless, identity theories have not been incorporated into health behaviour theories/models. To avoid theory duplicates and drive new development, we drew on Charmaz's (2014) grounded theory approach to develop a conceptual model that can be used to enhance understanding HIV-positive drug users' treatment-taking behaviour. In this approach, theoretical sensitivity and abductive reasoning are the key features for checking all possible theoretical explanations by empirically examining data and arriving at the most plausible explanation of mechanisms that influences

adherence (Charmaz, 2014). The development of a model in this study is to inform practice and to advance nursing science in HIV care.

Methods

The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to report this qualitative study (See Supplementary File 1).

Aims and questions

In this study, we set out to explore HIV-positive drug users' experiences of taking HAART, and to develop a conceptual model for unpacking the complexity of their HAART-taking behaviour.

The research questions that we sought to answer were:

Main research question:

What are the experiences of taking HAART among HIV-positive drug users in Taiwan?

Sub-questions:

1. What meanings do HIV-positive drug users attribute to their experiences of taking HAART?
2. What is the process of their HAART-taking behaviour?
3. What contributes to the stability and change of HIV-positive drug users' HAART-taking behaviour? Under what conditions?

Overall study design

This qualitative study took a social constructionist perspective (Denzin & Lincoln, 2018), and drew on a constructivist grounded theory approach that was consistent with the aim of developing a conceptual model (Charmaz, 2014). Knowledge was therefore conceptualised as interpretive and contextually situated (Charmaz, 2014). With its focus on the subjective and situated construction of experience, this approach provided a useful means for understanding drug users' experiences of taking HAART.

Study settings

Taiwan is a highly collective and hierarchical society (Zhang, Lin, Nonaka, & Beom, 2005). Such collectivism and hierarchy had an impact on facilitating and limiting access to study sites. In an attempt to gain support and access to study sites, a networking strategy was employed whereby the first author (SSH) was introduced to health and social care

professionals by a colleague who worked in the HIV field in Taiwan. By using this approach, colleagues at the study sites agreed to support this study and recruitment. The chain of social relations was built through the process of constant negotiation and interaction with stakeholders, resulting in gaining access to study sites.

Twenty-two HIV-positive drug users were recruited from three sites in Taiwan that provide HIV and addiction services to people who use drugs and are living with HIV: 1) HIV outpatient settings at a large hospital in Taiwan, 2) a non-government HIV association (operated in two capital cities in Taiwan), and 3) an addiction support association (multiple branches across Taiwan). The rationale for recruiting through multiple sites was to access the experience of a diverse range of people who use drugs and are living with HIV in Taiwan.

Recruitment and sampling

The criteria presented in Table 1 were to identify suitable participants and meet the research aims (**Table 1: Inclusion and exclusion criteria**).

Participants were recruited through health and social care professionals. During the recruitment period, health and social care professionals provided prospective participants with study information sheets and then gave them 1-3 weeks to think whether they would like to take part. If prospective participants were interested in the study, the researcher (SSH) would be introduced to the potential participants by health and social care professionals. This strategy was used in an attempt to enhance voluntary participation and to provide them with an option of not disclosing their contact information.

In total, there were 22 HIV positive drug users were recruited into the study, including 18 men of which 11 identified themselves as homosexual, 1 bisexual, 7 male heterosexual IDUs, and 3 female heterosexual IDUs (**Table 2: Socio-demographic information**). This is how the participants perceived to have contracted the virus. In Taiwan, HIV-positive drug users were mainly classified into two subgroups based on the transmission route—MSM (65% of the total HIV population, n=25,770) and IDUs (20% of the total, n=7,059) (CDC, 2020). In this study, the MSM group were infected with HIV through homosexual contact and used stimulants mainly for recreational purposes; the IDUs group were infected with HIV through sharing injecting equipment and were heroin injectors. In terms of gender, in Taiwan, males constitute 94.72% (n=37,573) of the total HIV population (n=39,669) (CDC, 2020). On the other hand, there were only 921 HIV-positive female drug users across Taiwan (CDC, 2020), which might include those in jail, those not receiving HAART, and those not in the recruitment sites. Concerned about the nature of illegal drug use, HIV stigma and social expectation of being female in Taiwan, it might have further increased the challenge of

recruiting female IDUs living with HIV in this study. Nevertheless, based on the HIV epidemiology in Taiwan, we would regard our study sample was the proportionality of the HIV population. Non-participation cases are listed in **Table 3**.

The sampling method for this study started with convenience sampling, and then moved to purposive sampling. The initial phase of convenience sampling was to gain insight into participants' experiences. Following the initial sampling and data analysis, sampling criteria for people, situations and settings were established for the following rounds of purposive sampling (Charmaz, 2014). For instance, four characteristics of the participants were identified during the process of data collection and analysis to influence their HAART-taking behaviour— Transmission route (unprotected sex or intravenous drug use), drug-using dynamics (heavy drug use or occasional drug use), gender, and the length of being diagnosed with HIV and on HAART (**Table 2**). These characteristics were then taken into account when framing sampling criteria during the data collection process.

Once tentative ideas about the data were developed, the later rounds of purposive sampling were to explicate and fill the incomplete categories. The incomplete categories meant that there remained some questions that did not give complete details of the categories, such as processes, behaviour patterns, outcomes, and contingencies.

The decision to stop data collection was made based on no additional questions (incomplete categories) and new theoretical insights found during the data collection period (September 2015 - July 2016).

Data collection

To facilitate the collection of rich data, face-to-face semi-structured in-depth interviews were conducted by SSH in Mandarin at a meeting room of the hospital or of the associations. The interview locations were chosen by participants due to a sense of security given by these trusting and familiar places. The interviews in this study were to explore participants' experiences of being HIV positive, taking HAART, and illicit drug use, all of which were potentially sensitive topics. Given the sensitive nature of the research, one-to-one interviews provided a more private and secure space for participants to share their personal experience than other data collection options such as focus groups.

Interview questions for this study were open-ended, general, and focused on the central phenomenon relating to HIV, HAART taking, and illicit drug use (**Table 4: Interview guide**). As the interview progressed, the interview questions were revised or added to depending on participants' responses to the questions. The interviews lasted between 45 and 140 minutes (audio-recording).

Translation

Translation of research data and findings between two different languages involves interpretation. To capture the meanings behind participants' stories and avoid loss of meanings, SSH analysed data in Mandarin. Once subcategories and categories in Mandarin were developed, the coded data were translated into English and then the data in English were re-analysed to develop codes, subcategories, and categories in English. The Mandarin and English versions of data, codes, subcategories and categories were compared to see their similarities and differences. Throughout the process, SSH moved back and forth between translation and data analysis and discussed the findings with RS and AH to develop a meaning-based translation. The detailed information with regard to the translation procedure of this study and the researcher's role during translation and data analysis is written in the paper by Authors (2019).

Data analysis

This study followed Charmaz's (2014) coding principles, which consist of two phases — an initial coding phase and a focused coding phase. An initial phase of coding involved line-by-line coding, and segment-by-segment coding. At this phase, the first author was open to all possible directions indicated by the data being read, and coding was named as close to the data as possible. In focused coding, similar codes were assembled together to analyse their commonalities, and then we attributed meanings to the organisation and layered the analysis into increasing levels of abstraction (codes -> subcategories -> categories -> concepts -> the interrelationship of the concepts -> a larger conceptual model) (**Table 5: Concept mapping**).

The analytic process involved induction (grounded from the data), deduction (authors' interpretations) and abduction (comparing and contrasting the findings with the existing theories and knowledge). These are essential steps of developing a theory/model in Charmaz's constructivist grounded theory (Charmaz, 2014).

Throughout the research process, two analytic techniques, constant comparison and memo writing (observational notes and analytic journals), were used to help capture the connections of data and codes across cases, and to crystallise questions and directions for further exploration. This study used NVivo software (version 10 and 11) to organise data and codes.

Trustworthiness

To ensure the trustworthiness of this study, we used excerpts from participants' interview transcripts to evidence our interpretations. Two or more sources of data were collected,

including interview data, socio-demographic information, observation notes, and research memos. Comparing different types of data during the analysis allowed to open up a more complex and in-depth understanding of participants' experiences. In addition, any uncertainties and questions that arose during the study period were discussed within the team to enhance the transparency of this study and minimise biases. To deeply explore participants' experiences and understand the meanings behind their stories, it was important to establish rapport with them. During data collection, our study participants were treated with respect, dignity and non-judgemental attitude. With their trust in the team, they appeared to openly share their experiences with us, which helped to enhance the credibility of the findings.

Ethical considerations

This study was approved by the ethics research committees of a teaching hospital in Taiwan (201507053RINA) and a Higher Education Institution in the UK (NURS011).

Prospective participants were provided with study information sheets regarding the purposes of this study, study procedure, participants' rights, data management and study contributions. Taking part in this research was completely voluntary. Participants were informed that they could withdraw at any time. Due to the sensitive research topic, all of the data were anonymised during transcription (by the first author). The data files were encrypted and saved on the university server, and the hard copies were securely kept in the locker of a secured university office.

Results

HIV-positive identity as part of self-identity, values attached to HAART, and conscious engagement emerged from the analysis to influence participants' HAART-taking behaviour.

Integrating HIV-positive identity into sense of self was revealed in the analysis to lay a foundation for HIV-positive drug users to accept themselves as HIV positive and the treatment. Valuing HAART appeared to play a central role in directing and driving their HAART-taking behaviour. Conscious engagement surfaced in the analysis to influence their maintenance of HAART-taking behaviour.

HIV-positive identity as part of self-identity (Figure 1)

HIV is a chronic and long-term health condition. In this study, many participants found it difficult to reconcile their sense of self with the implications of being HIV positive upon diagnosis. However, through the illness trajectory most participants integrated their HIV

status into their self-identity, and this in turn made them more accepting of antiretroviral treatment.

Non-integrated self-identity

HIV infection was viewed negatively by many participants. When not accepting HIV as part of HIV-positive self-identity, they were inclined to feel ashamed and not disclose their HIV status; thereby it could be proposed that this undermined their internal strength to manage HIV and its treatment.

“Getting HIV meant that my life was ruined, because when I was little, ads said that HIV infection was caused by promiscuity. The ads educated us to not have sex with many people and to remember wearing condoms; otherwise, you would get HIV... That’s why I felt HIV was a shameful disease.” (P10, Female heterosexual, 33y)

“The public thinks that HIV means gay men. I also think so. There is a reason behind it. You can see that why HIV incidence among heterosexuals is so low. There must be a reason behind it.” (P1, MSM, 28y)

Data revealed that HIV was portrayed as being associated with other attributes, such as promiscuity, homosexuality, and illicit drug use. This indicates that public perceptions of HIV surfaced mainly in respect to the ways affected individuals were infected. The multi-layered and negative social images of HIV were revealed within the analysis to influence the way participants evaluated themselves as HIV positive. For example, participants’ statements *“I felt HIV was a shameful disease”* (P10, female heterosexual, 33y), *“It is awful even just hear this word”* (P15, Male heterosexual, 53y), and *“It is a shameful disease”* (P16, male heterosexual, 42y) conveyed their feelings of shame by carrying the stigmatizing HIV-positive identity. When participants’ emotions towards “stigmatising HIV” were overpowering, the amount of knowledge they have learned relating to HIV was completely subsumed. This is exemplified by P2’s and P19’s stories.

“HIV is a chronic illness. If not controlling it well, it can develop AIDS. If it is controlled well by medications, we can live longer. It is just a statement. You feel like you still live with it day by day.” (P2, MSM, 32y)

“It is social value. While current medical technology is advancing, HIV is just a chronic disease, however, when it comes to social value, I think how to solve the issue of HIV stigma becomes difficult and unanswerable.” (P19, Male heterosexual, 43y)

Participants who perceived themselves negatively were inclined to lose their sense of self with HIV (inwardly), which further impacted their engagement with the treatment (outwardly).

"I felt ashamed of myself and avoided the crowd, starting to lose the sense of myself...Cocktail treatment is equated with HIV. It is the same thing. Most people wouldn't reveal what they are taking. I rarely saw people who took antiretroviral treatment. Even though they took it, they wouldn't reveal they were taking the medications. They wanted to save face. It's common in the Taiwanese society."(P7, MSM, 30y)

"They [medications] reminded me that I had problems in my body. This would affect my regular use of medications. I think that you may have heard other people viewed the treatment negatively and had many negative emotions. It just reminded me that I have HIV." (P12, MSM, 35y)

Living in the Taiwanese society where the image of HIV was negatively portrayed, most participants felt afraid and insecure to disclose their HIV status. This imposed limitations on them and created a barrier between self and others. As a result, not disclosing HIV increased participants' emotional burden and negatively affected their management of HIV and HAART.

"People don't know my condition and I need to conceal. I just don't want to explain to others what medications I am taking." (P18, Female heterosexual, 32y)

"Not many people would take the medications openly. To me, I cannot do it. I will try to avoid the risk. I've never taken my medications outside." (P1, MSM, 28y)

By and large, participants' HIV-positive identity appeared to undermine their self-acceptance of what they were and further influence their readiness and willingness of initiating and receiving HIV treatment.

Integrated self-identity

Participants, on the whole, demonstrated that their integration of HIV identity into their sense of self assisted them in viewing their HIV status more positively, and increased their willingness to face and manage HIV and HAART.

"I have gone through everything. It's important to be positive...I think it still depends on self." (P4, MSM, 26y)

In P4's account, his acceptance of the HIV-positive identity appeared to involve process and his experiential learning. Through reflecting on his HIV journey and finding meanings in his life with HIV, he was able to move forward.

"The scar will be there with you for the rest of your life. It depends on how you view it. If I think it is a scar on my face, I wouldn't get along with it well. If I think it is part of my body, I would try to make it pretty or cover it up. It depends on yourself." (P13, MSM, 31y)

Participant 13 used 'scar' as a way to describe the perceived negative label of his HIV-positive identity. His self-acceptance did not mean he liked what was happening but once he gave up the resistance and denial, he took the energy he was struggling and used it to manage HIV more wisely. His positive thinking and emotional adjustment seemed to have aided in treatment management.

In addition, a feeling of being supported was stated by some participants to provide a source of comfort in their troubled times, as well as a foundation for feeling unconditionally valued, loved and cared for.

"During this process, the HIV specialist always encourages me. I can feel the support. I feel thankful. I will bravely keep moving on. I need to take the responsibility of my life. Although it is painful to have HIV, this medical team is my only motivator to move forward." (P2, MSM, 32y)

Participants' statements as below illustrated that by feeling supported and finding meaning in life it seemed to motivate them and facilitate their willingness to face HIV and manage HAART— *"That's when they [family] reminded me to take medications. It was a big encouragement. They want me to live"* (P12, MSM, 35y), and *"This faith [Christianity] has greatly influence my regular use of medications"* (P4, MSM, 26y).

Values attached to HAART taking (Figure 2)

Valuing HAART emerged from our analysis as central to participants' HAART-taking behaviour. In this study, the degree to which participants valued HAART greatly influenced their motivation and engagement with HAART-taking.

Placing low values on HAART taking

Where participants placed low values on HAART this governed their state of motivation and HAART-taking behaviour. Placing such low values on regular HAART use was shaped by the degree to which participants believed in the importance of regular HAART use.

"Sometimes when I was sleepy, I would feel lazy to get up to take medications. I thought it was fine to take them next day. It doesn't happen frequently, less than 3 times a month. I don't care." (P6, MSM, 52y)

"I had treatment interruption because I was laid back. Hence I didn't go to hospital...Also, at that time my CD4 cell count was fine, at around 500. I thought it was fine to stop the treatment." (P16, Male heterosexual, 42y)

P6 has taken antiretroviral medications for 15 years and is a relative adherer, whereas data showed that he intentionally skipped doses sometimes. His statements— *"it was fine to take them next day"* and *"I don't care"* indicated that skipping doses few times did not concern him. Congruent with P6, P16's statements showed that his interpretations of the need for taking HAART and his laid-back approach influenced his medication-taking behaviour and led to treatment interruption for two years.

The values participants placed on HAART consist of cognitive, affective, motivational, and behavioural components. A cognition that involved interpretation and developed a conceived value (e.g. *"I thought it was fine"*, P6, MSM, 52y), an affection that provided feeling about the object (e.g. *"I don't care"*, P6, MSM, 52y), and a behaviour that was provoked when the value was activated (e.g. skipped doses). These were shaped through the process of participants' experiences. When not thinking and feeling the importance of taking HAART, participants were less likely to value it and to take HAART regularly.

In addition, for HIV-positive drug users, illicit drug use was found to influence the values they placed on HAART in two ways— Hierarchy of values (personal preference) and the impact of drug effects on changing personal values.

"I often went out at midnight for having sex and using drugs. When having fun, I wouldn't think of dosing times. I wouldn't finish it within 3-5 hours." (P1, MSM, 28y)

"Some would just crave for that euphoric effect, and constantly inject drugs to sustain that kind of feeling... Then would neither care what time it was nor notice dosing times" (P18, female heterosexual, 32y)

In P14's and P15's narratives, the psychoactive drugs they used affected their cognition, causing them to rationalise their drug-taking behaviour and to undermine their self-awareness.

"Because using drugs could distort my values and my worldviews. They were all changed and distorted. I wouldn't care about my health." (P15, Male heterosexual, 53y)

"When using a lot of drugs and for a long period of time, we would not have self-awareness. We wouldn't think of whether we needed to maintain health. I would feel why I should take the medications." (P14, MSM, 36y)

To sum up, it seems that participants prioritised what was important to them based on their beliefs and preferences. When valuing illicit drugs more than HAART, some were inclined to use drugs and intentionally ignore dosing times. On the other hand, the effects of illicit drugs on participants' cognition and emotion also influenced the values they placed on taking HAART.

Developing the values of taking HAART

From our analysis, we found that some participants began to value HAART through their acknowledgment on the benefits of taking HAART and the impact of erratic HAART use. Furthering this notion, their personal experiences emerged in the analysis to reinforce participants' motivation.

"HAART has increased my CD4 cell count, boosted my immune system, and made my viral load undetectable. This is a big motivator for me." (P2, MSM, 32y)

"It is better to not stop the treatment because it could cause drug resistance. If it happens, there won't be any treatment available for me." (P4, MSM, 26y)

Participants' narratives provide a sense that their acknowledgement of the pros and cons of receiving treatment influenced their perception and motivation. In addition to their acknowledgement, the desire to live longer and to take HAART was formed through participants' social relationships.

"I take the medications because my thought has been changed. Nowadays HIV is not that horrible and also I have a son. I want to live longer and see him grow up and have his own family." (P15, Male heterosexual, 53y)

"I want to live. I don't want to let my family down." (P11, MSM, 31y)

In particular, participants' feelings of support from family had given them hope and aspirations to live, thereby they valued HAART and felt motivated to regularly take the medications.

Conscious engagement (Figure 3)

Valuing HAART acted as a driving force to direct participants' HAART-taking behaviour. However, data revealed that to strictly follow a prescribed HAART regimen, participants needed to make a conscious effort and be mindful of their engagement with the treatment in the present moment and under the given situation.

Not consciously engaging with HAART taking

Participants' narratives demonstrate that the majority of them had forgotten to take HAART regimens at some point during their treatment trajectory. Their forgetfulness was found to be linked to their lack of conscious engagement in taking HAART at dosing times and in particular situations.

"When I watched movies, I didn't notice my pill box, and the dosing time passed...If you didn't notice it, you would forget. The next day, when I opened my pill box, I found out that I hadn't taken my dose yesterday." (P6, MSM, 52y)

P6's statement indicates how he lost track of dosing times. Without consciously engaging in taking HAART, some participants were less able to attend to and exercise control over their HAART-taking behaviour, leading to unintentionally missing doses.

"When I got back in the evening, I was tired. In other words, after taking a shower, I would want to sleep right away and then I forgot my doses. This incidence is rare, less than one time every 2-3 months." (P8, Male heterosexual, 49y)

In addition, without establishing a lifestyle that incorporated HAART into routines, participants, on the whole, demonstrated that the level of their conscious engagement with the treatment was lowered.

"If I am on a business trip for 1 or 2 nights, I would sometimes forget to take the medications with me. If I remember I would bring them. If I forgot, I would take it next day."

The excerpts from participants' interview transcripts — 'too many things' and 'busy at work', point that participants' involvement in other activities shifted their focus onto matters of concern other than HAART regimens, and increased the likelihood of missing doses.

Consciously engaging with HAART taking

From the analysis, we found that when participants took control over their behavior and external influences, they were more likely to manage long-term antiretroviral treatment more effectively. Participants' conscious engagement with the treatment involved a controlled and intentional process where they could reflect upon mental activity and foster self-control and self-adaptation so as to fit dosing schedules into their lives.

"Using drugs wouldn't affect my regular use of medications...As I mentioned earlier, you should know how to engage in chemsex and how to control self and not to be influenced by drugs. So I think it doesn't matter." (P9, MSM, 35y)

Drawing on participants' experiences, their self-control over drug use had helped to optimise their adherence to HAART. Self-control involved perseverance. The word — 'must', used by P10, conveys a sense of determination to continue regularly taking HAART.

"I know I must take the medications. I always tell myself I must take medications and I cannot miss doses." (P10, Female heterosexual, 33y)

In terms of adaptation, throughout the treatment process many participants were able to apply cognition and reason to develop strategies and adjust behaviour so as to take HAART regularly.

"I found that when I had the medications after my first bite of the meal, I would feel fine. I found this strategy." (P12, MSM, 35y)

"I usually use phone alarms to remind myself of taking medications. When it rang, I would take the medications." (P17, Male heterosexual, 37y)

In addition to the above, other strategies shared by participants included linking dosing times with daily schedules (P7, P20, and P21), placing medications at a visible place (P19, P22), using a pill box (P6 and P15), or significant others' reminders (P10 and P8).

By and large, participants who adhered to HAART in this study tended to have a heightened sense of situational awareness in relation to taking HAART, and were willing to exert cognitive efforts for regular HAART use.

Discussion

Three major concepts emerged in the analysis to influence HIV-participants' treatment-taking behaviour: 1) HIV-positive identity as part of self-identity, 2) Values attached to HAART, and 3) Conscious engagement. The three concepts were integrated into a conceptual model to understand participants' behaviour change and maintenance— Identity-Values-Conscious Engagement Model (**Figure 3**). This proposed model suggests that individuals' integration of HIV-positive identity into sense of self can provide a foundation for HIV-positive individuals to accept themselves and the antiretroviral treatment. Having this integrated identity, valuing of taking HAART plays a central role in driving and guiding their HAART-taking behaviour. While valuing HAART can trigger behavioural changes, we found that conscious engagement is an important element for sustaining their regular HAART use.

Identity is defined by Sharma and Sharma (2010) as "*an individual's comprehension of him or herself as a discrete, separate entity* (p.119)." Self-identity is an ongoing process of construction whereby one develops and forms a sense of self through personal experience

and social interactions (Karnilowicz, 2010; Stryker & Burke, 2000; Williams, 1984). In this study, participants' negative perceptions of HIV were deeply grounded in social values, wherein HIV was negatively portrayed by the Taiwanese society. The new HIV-positive identity altered some of the participants' fundamental meaning structures of what they are, leading to the uneasy balance between seeing HIV as an external force but yet feeling it affecting all aspects of their lives. On the other hand, with a coherent sense of self-identity, participants were more inclined to accept themselves and their treatment. These findings resonate with Baumeister's (1999) concept of self-congruence. He contended that self-acceptance and perceived acceptance from others can decrease internal conflicts (Baumeister, 1999), and thus enhance psychological well-being necessary to fulfil self-integration into society, and provide a blueprint for the least conflicted plan of actions (Pierce et al., 2003). This reflects the importance of continuing to decrease HIV-related stigma, through public health programmes and policies, and also to decrease stigma attached to the groups of individuals who are at an increased risk of HIV and marginalised within society such as homosexuality or intravenous drug users.

In terms of values, the role of values in an individual's health behaviour has not been extensively investigated in the current evidence base. Therefore, this study provides an important opportunity to advance the understanding of this concept and how it can influence individuals' HAART-taking behaviour. Values emerged in our analysis to play a core role in driving participants' HAART-taking behaviour. Values are defined, in this study, as a reflection of what an individual deeply believes to be important and necessary. Participants' decision to regularly take HAART was centred around what mattered to them and what they wanted. This is the deep-seated values that drive and guide their HAART-taking behaviour. The concept of values in this study is similar to the concept of beliefs elucidated in the *Health Belief Model* by Rosenstock et al. (1994), and the concept of motivation/intention in *Protection Motivation Theory* by Weinstein (1993) and *Theory of Planned Behaviour* by Ajzen (1991). These concepts theorise how individuals' perceptions of health and health behaviour can influence their motivation to act. However, the concepts of beliefs and motivation/intention elucidated by the aforementioned theories were in a sense of being led by rationality. Aside from rationality, individual preference/tendency was found in this study to shape the values participants placed on regular HAART use. Preference conveys an individual's tendency to choice, leading to value hierarchy (Rokeach, 1973). The hierarchical order of individual values is proposed by Rokeach (1973) to steer sequences of an individual's acts. In this study, participants tended to prioritise what was important to them. The more an object had value to the participants, the more they preferred it over the other despite the other being more rational. When the values they placed on drugs and HAART

were in conflict, some were in favour of pursuing chemsex or injecting drugs but ignored HAART regimens. Therefore, the notion of “Values” developed in this study provides a deeper sense of beliefs that can drive individuals’ acts (Rokeach, 1973).

To manage and sustain long-term and regular HAART use requires conscious behavioural control. Conscious engagement is referred to as a process where an individual reflectively and intentionally make regular HAART use possible and adapt to the external environment by fostering self-control and self-adaptation. The findings of this study suggest that without consciously engaging in HAART taking, participants tended to unintentionally forget and miss doses. This was especially common when participants were tired or busy. In addition, when heavily using drugs, many participants complained drug effects impaired their memory and levels of consciousness. These external influences undermined their ability to consciously manage HAART taking. These findings fit with existing evidence that HIV-positive drug users were more likely to miss doses (de la Hera et al., 2011; Harzke et al., 2004; Mimiaga et al., 2010; Witteveen & Ameijden, 2002). On the other hand, by consciously and strategically engaging in HAART taking, participants were able to adapt to the external influences and regularly take HAART. The concept of conscious engagement is grounded in the data and also inspired by the existing theories – Ajzen’s Theory of Planned Behaviour (1991) and Bandura’s Social Cognitive Theory (1991 and 2001) where the emphasis was placed on how individual behaviour can be regulated by self-consciousness and self-monitoring. Congruently, the empirical literature also indicates that some HIV-positive drug users were able to develop strategies to manage HAART taking (Mimiaga et al., 2010; Ware et al., 2005; Witteveen & Ameijden, 2002). However, these empirical studies did not explore the mechanism that underpins their coping ability. Thus, the findings of this study add knowledge to fill the gap in the current evidence base and provide a more comprehensive understanding of HIV-positive drug users’ experiences of managing long-term antiretroviral treatment

Conclusion

To conclude, this study aimed to deeply explore HIV-positive drug users’ experiences of taking HAART in the Taiwanese context and subsequently develop a conceptual model based on their experiences. Though it has been documented that HIV-positive drug users were less likely to adhere to HAART compared to the general HIV population, the mechanisms underlying such behaviour remained unclear. This study advances our understanding of HIV-positive drug users’ HAART-taking behaviour through key insights into 1) HIV-positive drug users’ contextually situated experiences of taking HAART in Taiwan, 2) the complex interplay of HIV-positive drug users’ illicit drug use and HAART-taking

behaviour, and 3) the development of the Identity-Value-Conscious engagement Model that can be applied to understand HIV-positive drug users' health behaviour changes and maintenance.

Relevance to clinical practice

This study has several implications. Firstly, within the HIV care continuum, nurses play a crucial role in supporting HIV-positive drug users during their treatment process, and often have a close connection to them. Within this relationship it is important to address common barriers to taking HAART. At the beginning of HIV trajectory, many participants experienced emotional distress. This finding suggests that upon diagnosis of HIV, nurses need to pay a particularly close attention to HIV-positive drug users' psychological well-being by eliciting HIV-positive drug users' concerns, feelings, and perceptions of being HIV positive and taking HIV medications. This study offers evidence that patients' sense of self can also be affected by the social context where feelings and thoughts arise. Thus, this study suggests that nurses should understand their support system, support them to develop strategies for HIV disclosure and acquisition of support, provide referrals to community support services, and be a moderator between clients and their families if they agree.

Secondly, valuing HAART appeared to be the driver of HIV-positive drug users' HAART-taking behaviour. Nevertheless, helping HIV-positive drug users to begin to value HAART requires our patience and prolonged engagement with them, as it takes time for HIV-positive drug users to perceive the importance of regular HAART use, and to develop the mindset of valuing it. The meaning of regular HAART use is constructed through HIV-positive drug users' interaction with others and how they perceive themselves and the world. Part of the treatment journey involves HIV-positive drug users' gradual discovery and development of values attached to HAART. In that sense, it implies the importance of providing constant support to this group of the population with patience, non-judgemental attitude, and compassion. Thus, this study recommends nurses to regularly assess HIV-positive drug users' needs, provide education and emotional support throughout the process of HIV care. Motivational interviewing techniques can be undertaken to enable clients to think through the pros and cons of regularly taking HAART, and peer support can be facilitated to provide practical issues they commonly encounter and strengthen their will to make behaviour changes.

Concerning the need for long-term management of taking HAART, forgetting to take doses was common among HIV-positive drug users in this study. This was mainly attributed to their tiredness/busyness, non-incorporation of HAART into everyday life, changes of environment,

or drug effects. To minimise external influences, the findings in this study suggest that nurses can support clients to identify situations where they would be more likely to forget taking doses, and to develop strategies that can help them effectively manage regular HAART use.

While this study can make contributions to knowledge within the field of HIV, addiction, and behavioural research, there are two major limitations. Firstly, the aim of this study is to develop a conceptual model of HIV-positive drug users' experiences of taking HAART. However, due to a small number of female HIV-positive drug users in Taiwan (n=921) (CDC, 2020) and the possible influence of social expectation towards the female gender, only three female participants agreed to take part in this study. Thus, the findings in this study may not be able to fully convey female HIV-positive drug users' experiences of taking HAART. Secondly, structural factors, particularly infrastructural factors (e.g. accessibility of HAART), were not identified within the findings, and were not found to be the main concern for the majority of participants. Despite this, the conceptual framework developed in this study provides useful insight and is potentially transferable to other social contexts, offering opportunities to explore and examine the structural element. We recommend that further work is needed to examine the applicability of this model in different social contexts and develop an intervention based on this model to address the needs of this population and optimise their treatment adherence.

What does this paper contribute to the wider global clinical community?

- This study provides insight into HIV-positive drug users' experiences of taking antiretroviral medications
- The findings extend our knowledge on the complex interplay of HIV-positive drug users' drug-taking and HAART-taking behaviour
- The Identity-Value-Conscious engagement Model developed from this study can be applied to help understand behaviour change and maintenance in relation to adherence to antiretroviral treatment among HIV-positive drug users.

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Table 1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Individuals are eligible to participate in the study if they are: 1) HIV-positive 2) at least 20 years old (individuals under 20 are under the care of a legal guardian in Taiwan) 3) able to complete the interviews in Mandarin 4) illicit drug users (current and past) 5) have been on HAART regimens	Individuals are not eligible if they are: 1) HIV-negative 2) less than 20 years old 3) not illicit drug users 4) currently hospitalised or in prison 5) unable to give informed consent 6) not on HAART

Table 2: Socio-demographic information

Participant	Sexual orientation	Transmission route	Type of drugs used	The frequency of using drugs	Length of being diagnosed with HIV	Length of using HAART
P1	MSM	Homosexual contact	Amphetamine, Ecstasy	4-6 times/week	4 years	4 years
P2	MSM	Homosexual contact	Amphetamine, Ecstasy	Once/week	6-7 years	6-7 years
P3	MSM	Homosexual contact	Amphetamine, MDMA, Ketamine, Marijuana	2-3 times/week	6-7 years	6-7 years
P4	MSM	Homosexual contact	Amphetamine, MDMA	4-6 times/week	3-4 years	2 years
P5	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	>10 times/day	8 years	2 years
P6	MSM	Homosexual contact	Heroin, Ketamine, Amphetamine	>7 times/week	16 years	15 years
P7	MSM (bisexual)	Homosexual contact	Amphetamine, MDMA	1-3 times/month	5-6 years	5-6 years
P8	Male heterosexual	Sharing injecting equipment	Heroin, Marijuana, Amphetamine, Opioid, Cocaine	>10 times/day	11 years	10 years
P9	MSM	Homosexual contact	Amphetamine, MDMA, Ketamine	5 years	7 years	3 years
P10	Female heterosexual	Sharing injecting equipment	Heroin, Amphetamine, MMA, Marijuana	>10 times/day	10 years	5 years
P11	MSM	Homosexual contact	Amphetamine, Ketamine, MDMA, Marijuana	1 time/week	4 years	4 years
P12	MSM	Homosexual contact	Amphetamine, MDMA	1 time/week	2 years	2 years
P13	MSM	Homosexual	MDMA,	MDMA:	6-7years	3 years

		contact	Ketamine, Marijuana, Amphetamine	once/week; Ketamine: 4- 6 times/day		
P14	MSM	Homosexual contact	MDMA, Ketamine, Amphetamine	MDMA: 3 times/month) ; Ketamine: 4-5 times/day	6 years	4 years
P15	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	>10 times/day	9 years	7 years
P16	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine, Cocaine MDMA	3-4 times/day	10 years	Started it 3-4 years ago (Have taken for three years) - > treatme nt interrupt ion -> Restart ed 1 year ago (have taken for one year)
P17	Male heterosexual	Through contaminated tattoo needles.	Heroin, Amphetamine	15 times/day	13 years	5 years
P18	Female heterosexual	Sharing injecting equipment	Heroin Amphetamine	5-6 times/day	8 years	10 months from her previou s pregnan

						cy. Now treatme nt interrupt ion
P19	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	2-6 times/day	8 years	10 months
P20	Female heterosexual	Sharing injecting equipment	Heroin, Amphetamine, Ketamine, MDMA	2-10 times/day	12 years	3 years
P21	MSM	Homosexual contact	Amphetamine, Marijuana, Cocaine, MDMA	Everyday	2 months	2 months
P22	Male heterosexual	Sharing injecting equipment	Heroin, Amphetamine	2 times/day	12 years	1 year

Table 3: Non-participation cases

Missing Case	Reason
1	Missed appointments
2 (Coupled with 3)	Did not come to the appointment
3 (Coupled with 2)	Showed up in the outpatient setting unexpectedly and left quickly
4	Hospitalised due to low CD4 cell counts
5 (Coupled with 6)	Could not reach her
6 (Coupled with 5)	Could not reach him

Table 4: Interview guide

Guideline for the semi-structured interviews	
<ul style="list-style-type: none"> • Self-introducing the interviewer (the first author) • Creating a comfortable and welcoming interview environment 	
Questions guideline (interview questions may change based on participants' answers)	
<p>Initial questions:</p> <ul style="list-style-type: none"> • Tell me about your experience with being HIV positive. Probe: What HIV means to you? What contributed to this feeling? • Tell me about your experience with drug misuse. Probe: How you feel about this? Why? How you managed? • How does being HIV-positive and drug use impact on your life? Probe: What happened? Under what conditions? How you managed? 	
<ul style="list-style-type: none"> • Tell me about your experiences with HIV treatment? • What does HIV treatment mean to you? Probe: What contributed to this feeling? • How do you feel before and after taking this regimen (At beginning versus years later)? Probe: Tell me why your views and/or actions may have changed (if any)? What have you learned? • Has there ever been a specific time when you haven't taken your medication? Probe: 1) Why? 2) Please describe the situation. 3) What contributed to this change or continuity? 4) What helps you to manage? • Who and what support you throughout the treatment course? 	
<p>Ending questions</p> <ul style="list-style-type: none"> • Is there anything else you would like me to know or to ask me? 	

Table 5: Concept mapping

Concept	Category	Sub-category
HIV-positive identity as part of self-identity	Non-integrated self-identity	Shame and self-stigma
		Non-disclosure of HIV status
	Integrated self-identity	Accepting HIV status
		Selective disclosure of HIV status
		Feeling supported
Values attached to HAART taking	Placing low values on HAART taking	Forming negative assumptions about HAART
		Not perceiving the importance/need of and disinterest in regular HAART use
		Placing values on drugs more than HAART
	Developing the values of taking HAART	Perceived benefits of HAART taking and perceived severity of erratic HAART use
		Having life aspirations
Conscious engagement	Not consciously engaging with HAART taking	Developing the mindset of valuing HAART taking
		Lack of conscious awareness of HAART taking
	Consciously engaging with HAART taking	Not incorporating HAART into everyday life
		Self-control over HAART-taking and drug-taking behaviours

Figure 1: Self-identity as the foundation that influenced participants' medication-taking behaviour



Figure 1: Values as the core construct that drove participants' medication-taking behaviour

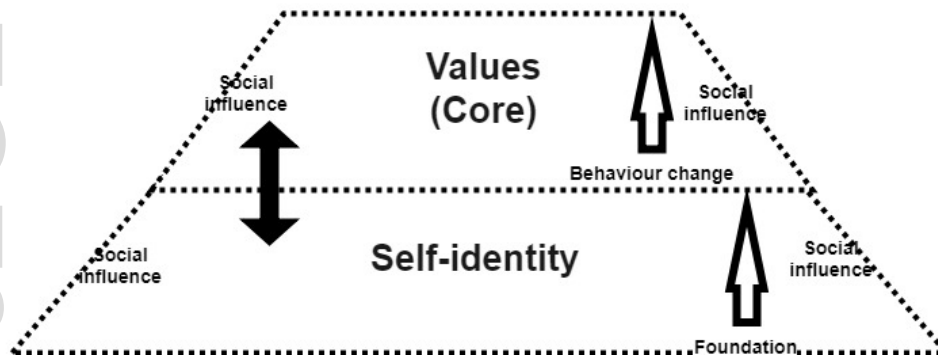


Figure 1: *Conscious engagement as the key factor that sustained participants' adherence to HAART*

